

Autism Spectrum Disorders:

Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment



A 2010 CONSENSUS PUBLICATION

Missouri Autism
Guidelines *Initiative*

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Funding for the printing and dissemination of the *Guidelines* was provided in whole by the Missouri Foundation for Health. The Missouri Foundation for Health is a philanthropic organization whose vision is to improve the health of the people in the communities it serves.

This publication, along with the full Guidelines and other support materials, are available at no charge at www.autismguidelines.dmh.mo.gov.



Missouri Autism Guidelines:

A CLEAR PATH TO FAMILY-CENTERED CARE

The words “autism spectrum disorders” can be overwhelming for a family to hear. But the fact is that early diagnosis and treatment of ASDs can greatly improve a child’s ability to learn, socialize, and build a productive life. That’s why a panel of 42 parents and professionals have worked together to produce the state’s first best practice guidelines for screening, diagnosing, and assessing ASDs, tailored specifically to Missouri families.

Now families can be assured that there are clear processes in place to guide healthcare and mental health professionals through these critical early steps toward intervention. That means real help and better outcomes for children and families throughout Missouri.

Georgina Peacock, MD, MPH, of the Centers for Disease Control, has noted this about *Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment*, “Children with ASDs and their families will definitely benefit from the information and thoughtful collaboration that has occurred as result of compiling these *Guidelines*.”

This booklet provides an overview and summary of the best practices contained in the *Guidelines*. The full *Guidelines* publication is available at no cost online at www.autismguidelines.dmh.mo.gov. Here is some of the important information families will find in the *Guidelines*:

- A clear definition of autism spectrum disorders (page 4 of this booklet).
- A list of key terms families will encounter as they help their child through the screening, diagnosis, and assessment processes (page 5 of this booklet).

- A set of flowcharts that clearly outlines the screening, diagnosis, and assessment processes (pages 15, 19, and 22 of this booklet).
- An outline of who is qualified to screen (page 12 of this booklet) and who is qualified to diagnose ASDs in Missouri (page 9 of this booklet).
- A list of red flag indicators to help families identify potential developmental delays (page 21 of the full *Guidelines*).
- A series of case examples that help illustrate how families, clinicians, and educators can best work together in the screening, diagnosis, and assessment processes (pages 30, 31, 38, 50, 52, 54, and 96 of the full *Guidelines*).

Family-centered Care. Throughout the *Guidelines*, the role of the family is central. The *Guidelines* acknowledges that that parents and caregivers know their children best and should be treated as equal partners. That means respecting each family's needs, priorities, and resources.

Working Together. Backed with this information, families will know what to ask and what to expect from healthcare and mental health providers, educators, and other service providers, including state agencies. The *Guidelines* spells out the role of each of these professionals in helping families with individualized care in a community collaboration model. Although these services will vary from family to family, their goals are the same: The healthy development and well-being of each individual and family.

The Overview and Best Practices that follow are excerpted from the full *Guidelines* publication as a summary of the key concepts and practical tools contained in the publication. The best practices describe the level of care that families should expect from their healthcare providers. The full *Guidelines*, written primarily for clinicians, is available at no charge at www.autismguidelines.dmh.mo.gov.

Introduction

These *Guidelines* provide recommendations, guidance, and information about current best practice in screening, diagnostic, and assessment services for individuals with autism spectrum disorders (ASDs). Tailored for Missouri health and education professionals and families of individuals with ASDs, the *Guidelines* are intended to help with informed decision making regarding identification, diagnosis, and assessment for intervention planning. These *Guidelines* represent general consensus among members of the Missouri Autism Guidelines Initiative regarding the publication's content and intended use. Although its content is informed by current literature and research, the document is not intended to provide an extensive review of related research.

The information is organized into three major chapters: screening, diagnostic evaluation, and assessment for intervention planning. Each chapter is written to stand alone to facilitate understanding and implementation by various groups. For that reason there is some repetition of key concepts from chapter to chapter. Each chapter includes a variety of tools to assist the reader to better understand the text and its applicability to practice. For example, Best Practice Recommendations are distilled from the text and printed in side bars. They are also summarized in Appendix A. In addition, case examples have been developed to further expand on key points within the text.

Autism Spectrum Disorders (ASDs)

ASDs DEFINED

Autism spectrum disorders (ASDs) are a group of neurodevelopmental disorders characterized by impaired social interaction and communication and by restricted or repetitive behaviors. These features are generally identified by the age of 3 years and are frequently associated with other physical and mental health conditions. The developmental challenges and associated problems in individuals with ASDs vary widely. Symptom presentation and degree of impairment can vary not only among individuals but also within the same individual over time.

The *Diagnostic and Statistical Manual, 4th edition, Text Revision (DSM-IV-TR)* published by the American Psychiatric Association (2000) is the current standard for the diagnosis and classification of ASDs by health or mental health professionals. The conditions on the autism spectrum addressed in these *Guidelines* include the *DSM-IV-TR* categories of Pervasive Developmental Disorders: Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and Asperger's Disorder. Use of the *DSM-IV-TR* for formal diagnostic classification requires specialized clinical training. A revision of the *DSM-IV-TR* is anticipated in 2012, and several issues are expected to be addressed in the **new** *DSM-V* that includes revision of specific ASD constructs that may impact ASD diagnosis. These *Guidelines* address issues related to screening, diagnosis, and assessment for intervention planning in a comprehensive and flexible manner that are likely to be adaptable to any changes in *DSM* constructs or criteria.

IMPACT OF ASDs ON FAMILIES

Scientific research has documented several ways in which families are impacted by having a child with an ASD. Parents of children with ASDs experience greater stress, depression, anxiety, and other negative health outcomes than parents of children with other disabilities (Waisman Center, 2008). Further, caring for a child with an ASD is complicated and often requires access to many support services, including primary and specialty health care, early intervention and special education services, services provided by mental health providers, and other community re-

sources such as specially trained child care and respite providers. Families often report significant gaps in care, difficulties navigating the complex care system, and financial strain that add to the challenges of raising a child with an ASD (Missouri Blue Ribbon Panel, 2008). Current estimates indicate that ASD-related costs to society range from \$35 to \$90 billion annually (Ganz, 2007).

Definitions of Other Key Terms

ASD SCREENING

ASD screening refers to the use of specific standardized instruments to identify an individual's risk for an ASD.

ASSESSMENT FOR INTERVENTION PLANNING

Assessment for intervention planning is a term that describes the process of determining each individual's specific strengths and concerns to inform the intervention planning process.

BEST PRACTICE RECOMMENDATIONS

These *Guidelines* offer recommendations for best practice that are not intended to be interpreted as policy or regulation but as tools designed to help healthcare providers, educators, and families make informed decisions regarding screening, diagnosis, and assessment for intervention planning.

DEVELOPMENTAL SCREENING

Screening refers to the use of standardized instruments to identify and refine an individual's risk for developmental delays.

DEVELOPMENTAL SURVEILLANCE

Developmental surveillance is the routine monitoring and tracking of specific developmental milestones, typically by physicians and primary care providers (PCPs) at well-child visits. This process of recognizing children who may be at risk for developmental delays is also conducted by other community professionals such as teachers and child care workers who routinely come into contact with young children.

DIAGNOSTIC EVALUATION

The terms “diagnostic evaluation” and “evaluation” refer to the diagnostic process aimed at identifying specific developmental disorders that are affecting a person suspected of having an ASD and the rendering of a *DSM-IV-TR* diagnosis by a physician, psychologist, or other health or mental health professional.

EVALUATION TO DETERMINE ELIGIBILITY FOR SPECIAL EDUCATION AND RELATED SERVICES

In public schools, evaluation under the Individuals with Disabilities Education Improvement Act of 2004 (IDEA) refers to an evaluation process conducted by a multidisciplinary team, including parents, for the purpose of determining a child’s eligibility to receive special education and related services.

LEAD DIAGNOSTIC CLINICIAN

The term lead diagnostic clinician refers to the licensed physician, psychologist, or health or mental health professional with knowledge and experience related to ASDs who performs evaluations for ASD diagnoses. The lead diagnostic clinician may be the same professional who provides ongoing care or may be a consulting specialist.

PRIMARY CARE PROVIDERS (PCPs)

The term primary care providers refers to physicians (e.g., pediatricians, family physicians) and other healthcare professionals (e.g., nurse practitioners) licensed to provide a broad spectrum of preventive and general health care.

SERVICE COORDINATOR

In Missouri, many state departments, county developmental disability boards, and community mental health centers assign a service coordinator or case manager to an individual or family. The coordinator is responsible for developing the individual support or service plan and assists in finding service providers.

Guiding Principles for Missouri’s ASD Services

Several principles guided the development of this document: (a) family-centered care, (b) early identification, (c) informed clinical judgment, and (d) community collaboration. Each will be described below.

FAMILY-CENTERED CARE

Throughout these *Guidelines*, a family-centered frame of reference reinforces the concept of parents and caregivers as the most knowledgeable source of information about the child, acknowledges that the child and family are part of a larger community system, and sets the stage for ongoing collaboration and communication between professionals and family members. The needs, priorities, and resources of the family are understood to be the primary focus and are respectfully considered during each step of the process: screening, diagnostic evaluation, and assessment for intervention planning.

A family-centered frame of reference includes cultural sensitivity and regard for family and community diversity of cultural values, language, religion, education, socio-economic, and social-emotional factors that influence the family’s ability to cope with the challenges of an ASD. Families are treated as equal partners in the diagnostic evaluation and assessment for intervention planning processes in order to enhance their capacity to meet the needs of the individual with an ASD.

EARLY IDENTIFICATION

Early identification of young children with ASDs can lead to earlier entry into intervention programs that support improved developmental outcomes (Johnson, Myers, & the Council on Children with Disabilities, 2007; Sallows & Graupner, 2005; Wiggins, Baio, & Rice, 2006). Early intervention has been associated with gains in verbal and nonverbal communication, higher intelligence test scores, and improved peer interactions (Wiggins et al., 2006). A substantial benefit of early intervention is the positive impact on the family’s ability to interact in a manner that facilitates their child’s development and to have a greater understanding of their child’s disability and how it interacts with

family life (Committee on Children with Disabilities, 1994). Early identification and diagnosis (a) enhances the opportunity for effective educational and behavioral intervention, (b) results in reduction of family stress by giving the family specific techniques and guidance for decision making, and (c) improves access to medical care and other types of support (Cox et al., 1999). Early intervention can improve both developmental functioning and the quality of life for the individual and his or her family (Eikeseth, Smith, Jahr, & Eldevik, 2007; Howlin, 2008; Rogers & Vismara, 2008).

Best practice recommends that screening and diagnosis occur as early in a child's life as possible. The characteristics of an ASD usually appear before the age of 3 years, and ASDs can sometimes be diagnosed as early as 18 months (Charman et al., 2005; Eaves & Ho, 2004; Lord, 1995; Pinto-Martin, Souders, Giarelli, & Levy, 2005; Wimpory, Hobson, Williams, & Nash, 2000). However, the average age of diagnosis across the nation continues to be well past 3 years (Centers for Disease Control [CDC], 2007; Shattuck et al., 2009; Wiggins et al., 2006) often long after parents first express concern to physicians (Chawarska, Klin, Paul, & Volkmar, 2007; Interactive Autism Network [IAN] StateStats, 2009).

There also may be racial disparities in the diagnosis of ASDs (Liptak et al., 2008; Mandell & Palmer, 2009). In a study of children in the St. Louis metropolitan area who were 8 years old in 2002, Black children meeting criteria for an ASD were less likely than White children to have an autism diagnosis in their health records. Furthermore, the median age of autism diagnosis among Black children was 8.2 years old, whereas the median age of diagnosis for White children was 5.5 years old (Shattuck, Constantino, & Fitzgerald, 2008).

To improve detection rates, the American Academy of Pediatrics recommends general developmental screening tests be administered regularly at 9-, 18-, and 30-month well-child visits and has initiated national efforts to improve developmental screening in the primary care setting. Specific routine screening for ASDs is recommended at 18 and 24 months (Myers et al., 2007).

INFORMED CLINICAL JUDGMENT

Currently, there are no biomedical markers or laboratory tests for identifying children who meet the diagnostic criteria for an ASD.

Accurate identification is entirely dependent on obtaining a complete developmental history and on direct interaction and behavioral observations. The importance of informed clinical judgment by health or mental health professionals responsible for diagnostic evaluation of an ASD cannot be overemphasized (Bagnato, McKeating-Esterle, Fevola, Bortolamasi, & Neisworth, 2008).

Although identification of an ASD is usually made during childhood, it is important to recognize that an ASD is typically a lifelong disability that affects the individual's adaptive functioning from childhood through adulthood to varying extents. To diagnose an ASD, the clinician must be familiar with typical and atypical child development, including age-appropriate behaviors, and have training and clinical experience with the ASD population.

Because ASDs have been found across a range of cognitive abilities, differential diagnosis requires familiarity with the presentation of ASDs in individuals with impaired, average, and advanced cognitive abilities. Furthermore, clinicians must be skilled at distinguishing ASDs from other types of childhood psychiatric and developmental disorders.

Clinicians who make an ASD diagnosis shall have at a minimum:

- Missouri state licensure as a physician, psychologist, or other health or mental health professional; and
- advanced training and clinical experience in the diagnosis and treatment of ASDs and related neurodevelopmental disorders, including knowledge about typical and atypical child development and experience with the variability within the ASD population.

Rapid developments in conceptualization, measurement, and basic research on ASDs require a commitment to periodic review of new discoveries and current best practices. This necessitates ongoing education and training opportunities for diagnostic clinicians. The clinical challenge is to stay current with new methods of evaluation and treatment, learn about and obtain the latest screening and diagnostic instruments, and maintain an awareness of local and regional community resources that meet the child's and family's needs. Using these resources adds to the

clinician's diagnostic accuracy and allows for a better understanding of the individual, leading to better treatment and care.

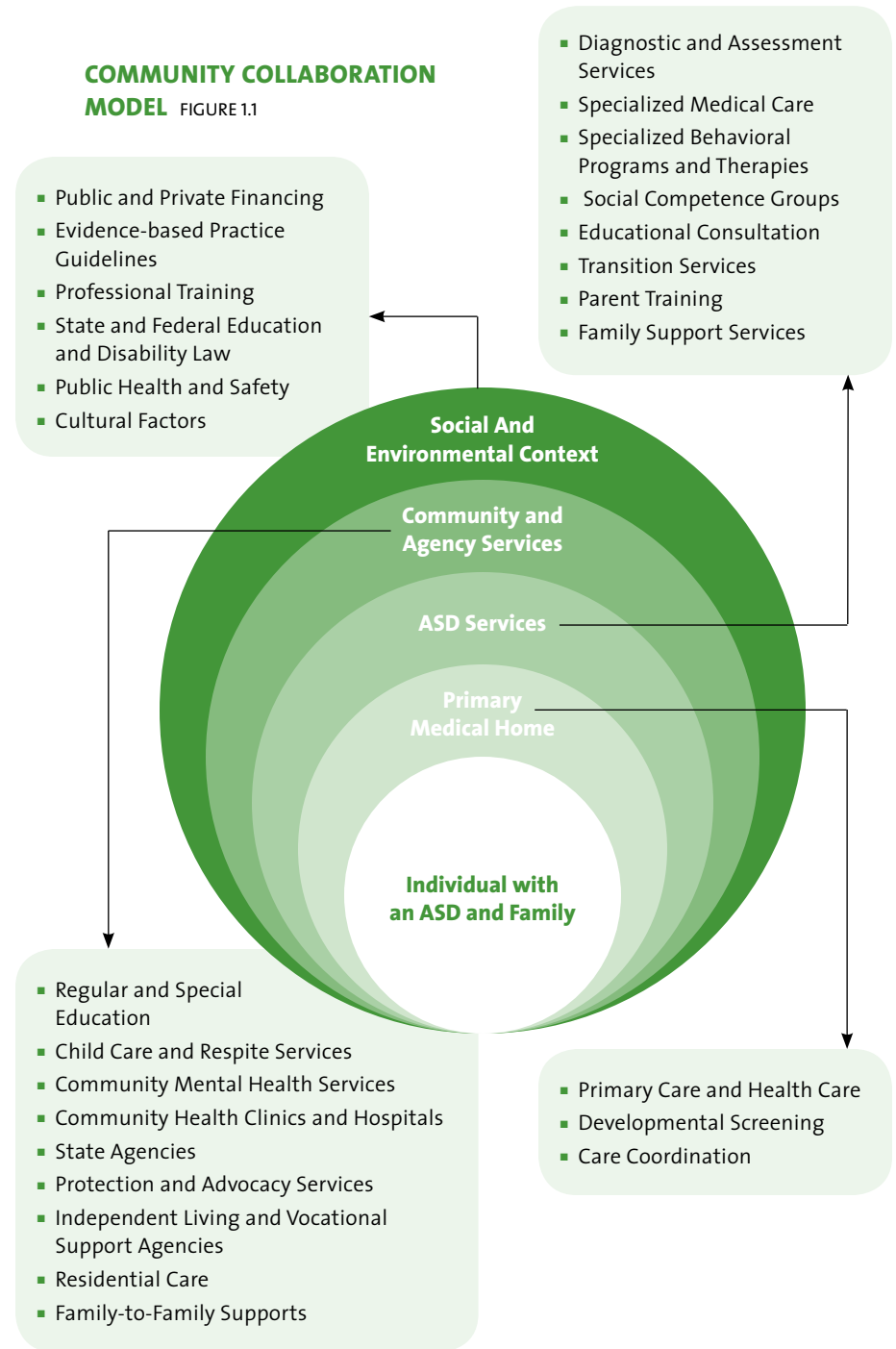
COMMUNITY COLLABORATION

Autism spectrum disorders affect multiple developmental domains. The complexity of these disorders necessitates a range of services that are tailored to the needs of families, from screening and referral services through diagnosis, assessment for intervention planning, and treatment. A comprehensive approach typically requires the involvement of a team of professionals from a number of disciplines (e.g., primary and specialty physicians, nurses, psychologists, speech-language professionals, audiologists, occupational therapists, social workers, behavioral and educational specialists, teachers). Consistent with national recommendations for ASD service delivery (Interagency Autism Coordinating Committee, 2005), these *Guidelines* promote interdisciplinary and interagency collaboration among the referred individual, the family, and the service delivery systems.

Missouri's approach to providing these comprehensive services acknowledges that an individual with an ASD and his or her family have available a wide range of services. In addition to ASD or disability-specific care, this framework acknowledges the individual's need to access community and agency services while also taking into account current social and environmental factors such as state laws, availability of public and private health insurance, and cultural factors (see Figure 1.1).

The concept of community collaboration is integrated throughout this publication as a way to promote discussion among clinicians, educators, state programs, researchers, and families as they move toward improved community-based services for persons with ASDs. Given that this model encourages interagency collaboration, it is recognized that the exchange of information among clinicians and agencies places ethical and legal responsibilities on those professionals to obtain informed consent and share only information that is clinically pertinent. Professionals are encouraged to discuss with families the many potential benefits of shared information across systems of care, including improved coordination of care among agency staff and professionals who can improve outcomes for the individual with an ASD.

COMMUNITY COLLABORATION MODEL FIGURE 1.1



In addition to developing processes to share pertinent information appropriately, professionals are encouraged to become informed about the similarities and differences among the various systems of care—organizations, agencies, and other entities—each of which has its own mission and related policies and procedures. Clinicians can then share this information and understanding with families.

Access to ASD Services in Missouri

Missouri's expanding networks of well-trained and experienced ASD clinicians are encouraged to work collaboratively to identify individuals at risk for ASDs and ensure accurate diagnostic evaluation and assessment for intervention planning. The intent of this collaborative approach is to improve outcomes for individuals with ASDs by promoting the early identification and timely entry into a full range of appropriate community-based services. This process consists of *three steps*: screening, diagnostic evaluation, and assessment for intervention planning. To assist the reader to better understand the publication's text regarding these processes, the authors have developed flow charts that describe each of the steps. Although the charts appear linear, the processes often are not, neither are they the same for all families.

SCREENING FOR AUTISM SPECTRUM DISORDERS

Screening for ASDs in Children Birth to Age Five

Early diagnosis depends on listening carefully to parents' concerns about their child's development and behavior. Current research suggests that the concerns of parents whose children were later diagnosed with developmental problems are generally accurate (Glascoe, 2001). Whether these concerns are heard by a pediatrician, family physician, nurse practitioner, child care provider, teacher, or other health or education provider, families are encouraged to make arrangements for children suspected of having developmental delays to be screened by a trained professional using standardized screening instruments and clinical judgment. Screening instruments are not intended to provide diagnoses but rather to determine whether there is a need for further diagnostic evaluation.

The American Academy of Pediatrics Council on Children with Disabilities recommends that pediatricians and other PCPs conduct developmental surveillance and screening as a part of routine well-child care (Myers et al., 2007). There are screening instruments that can be completed by parents and scored by non-physician personnel in a healthcare provider's office. All screening instruments have limitations, but the PCP should choose and become familiar with an ASD screening instrument for each age group and use it consistently. This document includes resources that can guide screening efforts. Table 2.2 in Chapter Two lists ASD Screening Instruments and provides information about how to access them. Appendix D-2 includes a copy of the *Modified Checklist for Autism in Toddlers (M-CHAT)*, validated for screening toddlers between 16 and 30 months of age to assess risk for ASDs. In addition, Appendix D-1 includes a list of screening instruments recommended for assessing general development. These instruments allow systematic detection of general developmental delays (e.g., delays in communication and cognitive functioning) that may be associated with ASDs in young children, but they are not designed to detect a specific ASD.

The PCP reviews the screening results with the family to support their efforts to understand their child's behaviors and encourages prompt action for further evaluation. PCPs also make the referral for a diagnostic evaluation, if indicated. When PCPs are unable to provide screening services, referrals for screening can be made to other trained providers in the community. Appendix E includes a list of resources for parents and professionals related to screening and, when appropriate, referral for diagnostic evaluation. Some of the materials and websites included on this list may be helpful to parents and professionals as initial discussions about ASDs unfold.

Screening for ASDs in Children Age Six and Older

Although the core impairments in individuals with ASDs are commonly identified in early childhood, a considerable number of children are not recognized as being at risk for ASDs until school age or later. In these cases, families, educators and/or young adults themselves may have concerns regarding social and communication impairments and atypical behaviors. Screening instruments designed for young children are not particularly useful in this age group. However, several screening instruments are available for use with older children and adolescents up to age

18. Professionals may consider additional sources of information across environments prior to referral, including behavioral observations, history provided by parents, and/or records about the child's developmental trajectory. Ultimately, if the professional or parent still has questions about ASDs, referral for further evaluation is warranted.

Referral for Diagnostic Services

When concerns arise that an individual may have an ASD, the family is consulted and a referral is made to a physician, psychologist, or other health or mental health professional who is licensed and qualified to make a diagnosis. Best practice suggests scheduling referrals as quickly as possible. The importance of expedited referrals cannot be overemphasized because recent research indicates that children with ASDs are not diagnosed, on average, until 13 months after initial screening by a qualified professional (Wiggins et al., 2006). Figure 1.2 summarizes the steps in the screening process that lead to referral for diagnostic evaluation and appropriate services and supports for the individual and his or her family when the screening result is positive.

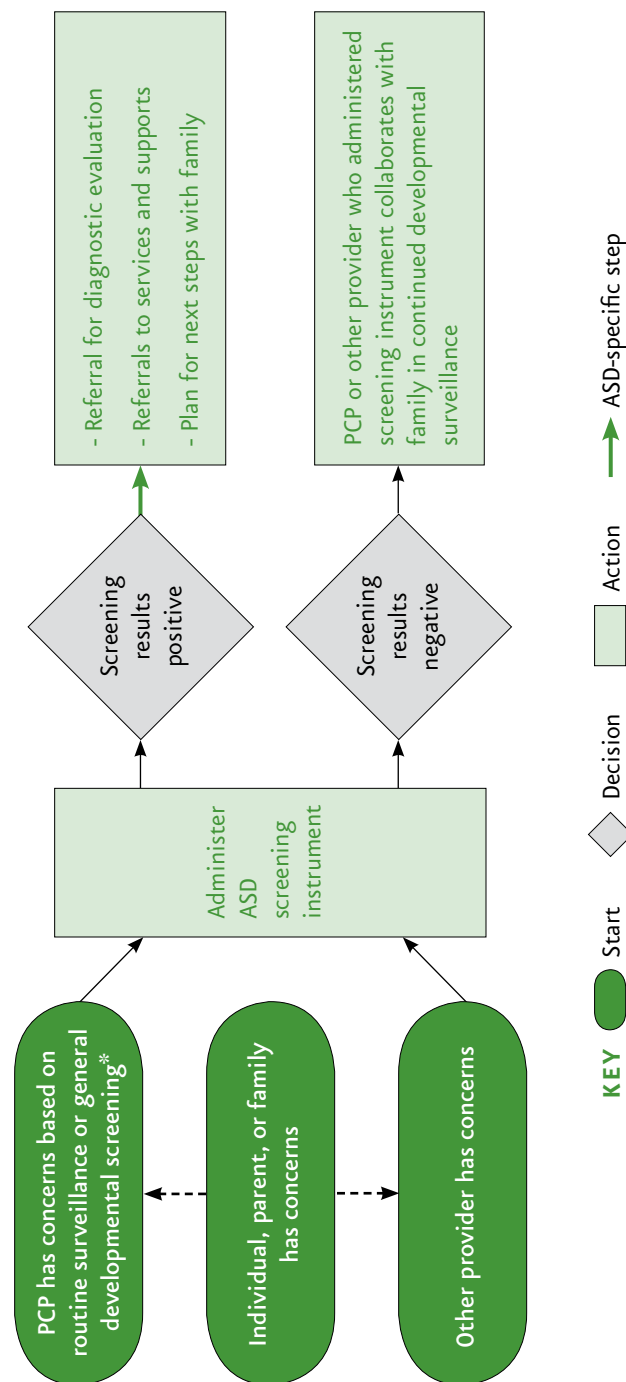
MISSOURI'S TIERED APPROACH TO DIAGNOSTIC EVALUATION

Diagnostic evaluation answers the question, "Is an ASD diagnosis warranted?" The purpose of the diagnostic evaluation is to collect sufficient data in the social, communication, and behavioral domains required by diagnostic criteria to determine whether an individual fits into a particular diagnostic category. In this document, the professional responsible for conducting the evaluation is referred to as the lead diagnostic clinician. This clinician must have the capacity to conduct an evaluation that includes two essential components: the individual's history and direct interaction with and behavioral observation of the individual.

In Missouri, a tiered approach to the diagnosis of ASD is recommended in order to provide access to diagnostic evaluation as early as possible without compromising diagnostic accuracy. The tiered approach is based on the recognition that the need for standardized measures and consultation with other professionals varies based on the presentation of the individual being evaluated and the clinical competencies of the lead clinician.

Diagnostic accuracy is impacted by four key elements: the lead diagnostic clinician's experience and judgment, the use of

THE PROCESS TO SCREEN FOR AUTISM SPECTRUM DISORDERS
FIGURE 1.2



* Routine screening by Primary Care Provider (PCP) is recommended at 18 and 24 months

standardized instruments, consultation with other professionals, and the complexity of presentation of symptoms. These key elements are described below.

Lead Diagnostic Clinician's Experience and Judgment

As noted, in Missouri the lead diagnostic clinician is a physician, psychologist, or other health or mental health professional who is licensed and qualified to render a diagnosis of ASD. This clinician may be practicing independently or as part of a larger multidisciplinary team and is responsible for collecting and reviewing adequate information so that the ASD diagnosis is based on current *DSM-IV-TR* criteria.

Use of Standardized Instruments

Specific standardized instruments are available that aid the clinician in gathering relevant information and evaluating specific ASD impairments (see Appendix F). Research has demonstrated that the use of these instruments adds incremental value to diagnostic accuracy (Lord et al., 2006).

Consultation with Other Professionals

As indicated, a single clinician's judgment can be enriched by including the perspectives of other specialists who interact with or have assessed the individual.

Complexity of Presentation of Symptoms by Individuals with ASDs

The severity of symptom presentation and the age of the individual can have an impact on the complexity of the diagnostic process and the accuracy of the diagnosis.

Levels of Diagnostic Evaluation

The approach in these *Guidelines* encourages the lead diagnostic clinician to determine the level of evaluation required for a diagnosis, with each advancing level incorporating increasingly sophisticated diagnostic methods, instruments, and consultation with other professionals. The lead diagnostic clinician selects the level of evaluation that best fits the needs of the individual being evaluated. For clarity, these *Guidelines* define the three levels of diagnostic evaluation as Tier 1, Tier 2, and Tier 3. (See Table 1.1.)

TIER 1: The lead diagnostic clinician determines that he or she is able to *independently* make a diagnosis or rule out an ASD based

on clinical judgment. The clinician may or may not choose to use standardized instruments to inform clinical judgment.

Tier 1 recognizes that there are individuals whose ASD symptoms are severe enough and/or whose diagnosis is clear enough to an experienced clinician that a diagnosis can be rendered without the immediate need for consultation with other specialists or use of standardized instruments.

TIER 2: When an individual has a more complex presentation, the lead clinician uses data from standardized diagnostic instruments and may also consider consultation with at least one other professional, as indicated, to inform his or her clinical judgment about whether an ASD diagnosis is warranted.

TIER 3: Individuals with very complex presentations (presentation with some ASD symptoms and multiple coexisting concerns, or complex medical or psychosocial history) may require an even broader and more sophisticated approach to inform clinical judgment about whether an ASD diagnosis is warranted. In these cases, the lead diagnostic clinician may work with a team of professionals who have specific areas of expertise such as speech-language, occupational therapy, medical specialties, or psychology. In these cases, use of a multi-disciplinary team often improves diagnostic certainty by drawing on diverse specialty knowledge and training.

	INDIVIDUAL PRESENTATION	USE OF STANDARDIZED INSTRUMENTS	CONSULTATION WITH OTHER PROFESSIONALS
TIER 1	Presentation of symptoms that unambiguously indicate an ASD	May be used; not required	None
TIER 2	Milder or more complex symptoms, difficult differential diagnosis, question about cognitive level	Yes	Possibly; consult with at least one other professional, as indicated
TIER 3	Very subtle or complex symptoms, some ASD symptoms with multiple co-existing concerns, complex medical or psychosocial history	Yes	Yes; consult with multiple other professionals

Clinicians should remain sensitive to parents' concerns regarding the completeness of the evaluation. For example, if the clinician conducts a Tier 1 evaluation and comes to a diagnostic conclusion but the parents remain concerned and request a more comprehensive evaluation (e.g., the parents feel that the evaluation was not representative of the child's typical functioning), the clinician involves other professionals for a higher tier diagnostic evaluation or refers the family to others for further diagnostic testing.

Several standardized instruments are available to assist with the diagnostic evaluation, as appropriate. A listing of diagnostic instruments is included as Appendix F.

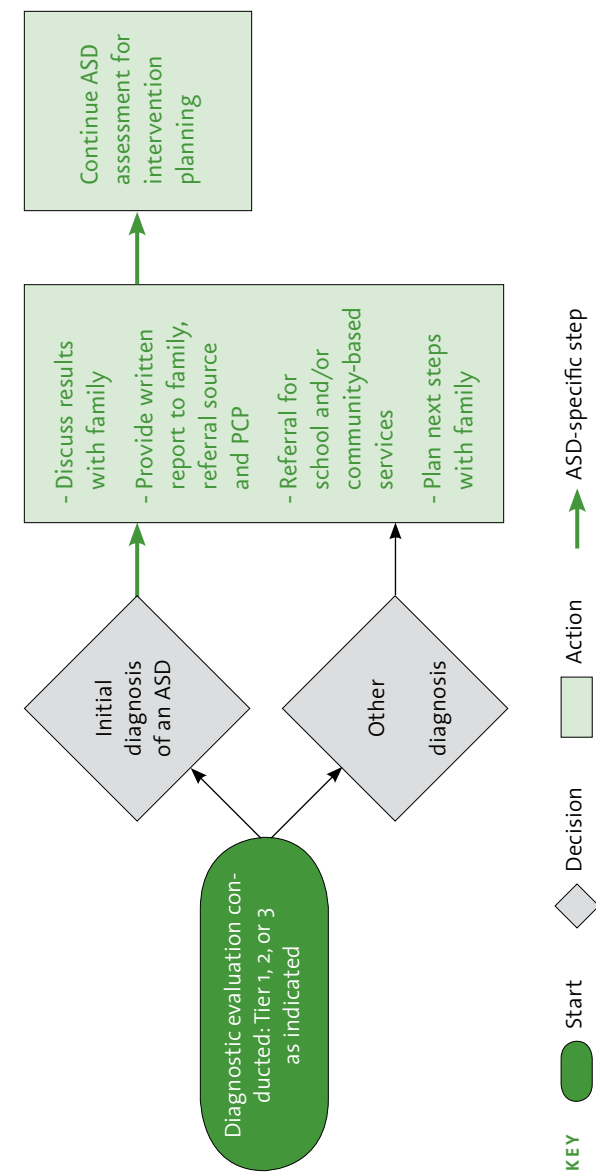
After conducting a diagnostic evaluation, the lead diagnostic clinician discusses with the family the outcomes of the evaluation, possible referral to other health professionals for further assessment to prepare for the selection of the appropriate intervention, and the family's preferences for follow-up care.

Importantly, throughout this process, the lead diagnostic clinician distinguishes between the *medical diagnosis* and *educational eligibility*. The medical diagnostic process seeks a diagnostic determination that leads to treatment recommendations, whereas educational evaluations are designed to determine whether the child meets the state's educational eligibility criteria for special educational services. The challenge often is to achieve the optimal level of collaboration and communication among the family and various professionals and agencies involved in the medical diagnosis and educational eligibility processes.

The diagnostic evaluation is designed to address issues that include parents' concerns, priorities, and resources. Parents often have questions regarding the meaning of the diagnosis for their child and family and the intervention approaches that can help them address the needs of *their particular child*. Best practice recommends that the lead diagnostic clinician build a partnership with parents and caregivers throughout the diagnostic evaluation process. This partnership recognizes and respects parents' expertise about their child and focuses on parent questions and concerns. The process of diagnostic evaluation is summarized in Figure 1.3.

THE PROCESS OF DIAGNOSTIC EVALUATION

FIGURE 1.3



ASSESSMENT FOR INTERVENTION PLANNING

Assessment is a continuous and ongoing process. It answers the question, “What individual strengths and concerns should guide intervention planning?” Although it is possible for an independent professional or professionals representing one or two areas of expertise to make an ASD diagnosis, assessment for intervention planning requires involvement of professionals representing multiple disciplines. Often these professionals are part of a network of services that includes medical, educational, and other community-based services, each with its own assessment process. Families work collaboratively with professionals from each of these service systems to integrate the various assessment findings into a comprehensive profile of the individual’s strengths and concerns. This profile becomes the family’s basis for planning for the selection of specific interventions.

These *Guidelines* focus primarily on *clinical/medical assessment* for intervention planning. In this context, assessment goes beyond the categorical diagnosis to examine the individual’s functioning across *multiple* domains with the express objective of directing treatment planning and intervention based on the child’s and family’s individual profile. The lead clinician collaborates with the family to determine the need for and priority of assessment related to each of the following essential components:

- cognitive and academic functioning;
- adaptive functioning;
- social, emotional, and behavioral functioning;
- communication;
- comprehensive medical examination;
- sensory and motor functioning; and
- family functioning.

Assessment in each component is based on family concerns, clinical indicators, the individual’s intervention history, and data available from prior assessments. Additional clinical assessment that is needed for intervention planning depends on the nature of the diagnostic evaluation, such as the areas of expertise of the professionals involved in the diagnostic process, the number of domains assessed, and the depth of the assessment in each domain. In Missouri’s tiered approach to diagnostic evaluation,

the extent of additional clinical assessment needed for intervention planning is directly related to whether the diagnostic evaluation was completed at Tier 1, Tier 2, or Tier 3.

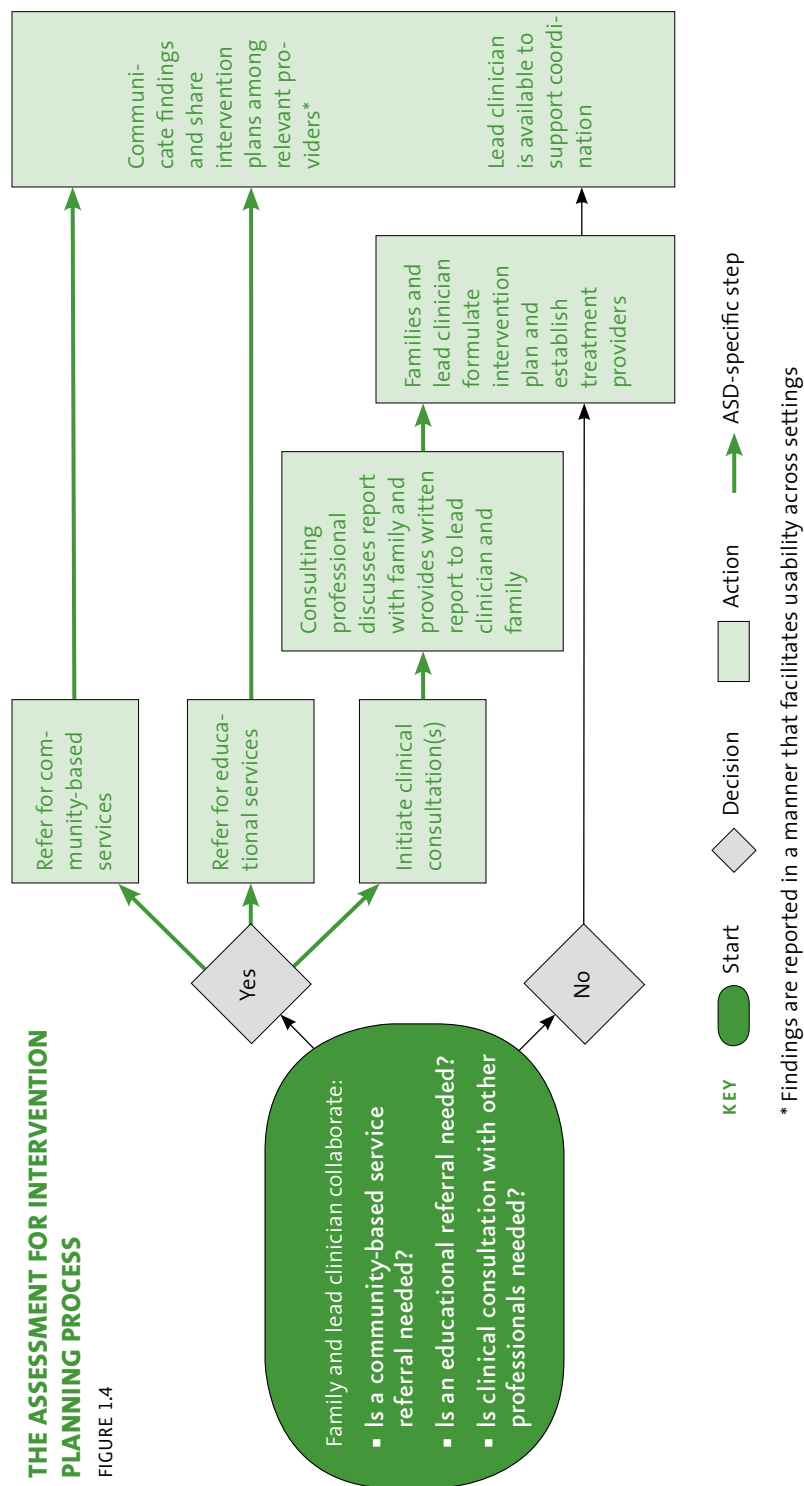
For each of the essential components listed previously, there are several instruments that can assist in the assessment process. Because of the complexity and quantity of information related to these instruments and their use in the assessment process, Chapter Four has been divided into two sections. Section One provides an overview of the process of clinical assessment for intervention planning. Section Two provides an in-depth discussion of the technical aspects of assessment of each of the essential components. In addition, Appendix G provides an extensive list of instruments for each of the essential components.

Diagnostic evaluation and assessment for intervention planning may or may not occur at the same time. However, multidisciplinary evaluations have the advantage of providing both diagnostic and assessment services at the same time and place, which may be an advantage for some families.

Assessment involves professionals representing multiple disciplines who have expertise in their own fields and specific training and experience with ASDs. Professionals are encouraged to discuss openly their credentials and experience with ASDs with individuals involved in the assessment process including parents or other family members. The lead clinician collaborates with the family to integrate the findings of the various professionals who contribute to the assessment process to create an individual profile that is detailed, concrete, and easily understood by the child’s family and other care providers, and that provides a basis for individualized recommendations regarding interventions. The assessment process is summarized in Figure 1.4.

THE ASSESSMENT FOR INTERVENTION PLANNING PROCESS

FIGURE 1.4



Although these *Guidelines* focus primarily on clinical assessment, schools and other community-based services often provide vital information that may be of assistance to comprehensive planning for intervention. Gaps in communication among these three service systems often are identified as a cause of confusion and frustration for individuals with ASD and their families. Therefore, it is essential for clinicians to understand the similarities and distinctions among these three systems. A brief discussion of the three systems follows. In addition, Table 1.2 compares assessments by clinical/medical, educational, and other service systems.

Clinical/Medical Assessment for Intervention Planning

Clinical/medical assessment (or clinical assessment) for intervention planning derives from diagnostic evaluation in which established medical diagnostic criteria (*DSM-IV-TR*) are used to make a medical diagnosis of an ASD. Clinical assessment for intervention planning addresses ASDs as neurobiological disorders that may manifest in multiple areas of neurodevelopment and require intervention across medical, educational, home, and community settings. Consideration of information from educators and community service providers enhances clinical assessment. Assessment results in a treatment plan that includes recommendations and referrals related to behavioral interventions; outpatient services such as specific medical treatment, medication management, speech and language therapy, occupational therapy, physical therapy, psychological intervention, or family therapy; educational strategies; and community-based resources and support services, especially those that may require a medical diagnosis or clinical documentation for eligibility. Clinicians also may inform families about opportunities for research participation.

An individual with a medical diagnosis of an ASD may or may not be eligible for special education services or other programs designed for individuals with disabilities.

Educational Evaluation and Assessment

Educational evaluation and assessment is a mandatory process under the Individuals with Disabilities Education Improvement Act of 2004 (IDEA)—the legal and regulatory basis for special education in public schools. The *Missouri State Plan for Special Education* (DESE, 2007) details how public schools in Missouri

will comply with the federal law when evaluating and educating children with disabilities. The First Steps program for young children ages 0–3 is administered under Part C of IDEA. In Missouri, a medical diagnosis of ASD for a child in this age range results in automatic eligibility for early intervention services up to age 3.

The process differs substantially for older children. Part B of IDEA defines students with disabilities as those children, ages 3–21, who have been properly evaluated by the public school and who meet the eligibility criteria under one or more of 13 educational categories. Autism is one of the 13 categories of education disability.

For the student to receive special education services, Part B of IDEA requires that the student meets the eligibility criteria under one or more of the eligibility categories specified in the law and demonstrates a need for special education services. Public schools do not *diagnose* students but instead determine *eligibility* for services. During the course of the educational evaluation to determine eligibility, educators draw upon information from a variety of sources and ensure that information obtained from these sources is documented and carefully considered. IDEA mandates that consideration be given to the results of evaluations from outside providers, but public schools are not required to accept the results or use them in program development. Sometimes this statement is misinterpreted to mean that educators do not have to accept the diagnosis of ASDs or other medical conditions. It is not the role of educators to challenge a medical diagnosis. However, a medical diagnosis alone is not sufficient to establish students' eligibility for special education services if they are in the 3- to 21-year age range. Eligibility decisions are based on evaluation of child behaviors in the educational environment to determine if the child satisfies the criteria under an education category specified in IDEA, whether the condition adversely affects the child's educational performance, and whether the child needs special education services. If eligibility is met, assessment in the educational environment must be sufficient to guide development of an Individualized Education Program (IEP). The IEP addresses the unique learning needs of the child in the educational environment, which may be similar to or different from the needs of the child in other environments. The IEP is reviewed and revised at least once annually.

In some cases, students with ASD medical diagnoses may qualify for educational accommodations under a 504 Plan (Rehabilitation Act of 1973) even if they do not meet special education eligibility criteria in the Autism category. A 504 Plan establishes accommodations and modifications that can be integrated into the general education curriculum, such as extra time for test completion. This approach is an accepted practice for students with special needs who do not qualify for services under IDEA. Additional information can be obtained at http://www.moddrc.org/fast_fact.php?disID=146.

Students who receive special education services based on criteria in the Autism eligibility category may or may not meet criteria for an ASD medical diagnosis and may or may not be eligible for other programs designed for individuals with disabilities.

Assessment by Other Service Providers

Other service providers typically utilize agency or organization-specific assessment procedures for eligibility determination and service planning. For example, eligibility for Department of Mental Health (DMH) services is based on state guidelines. Assessment is conducted to determine eligibility and to guide service provision for eligible individuals. DMH services typically require a medical diagnosis of an ASD and documentation of impaired adaptive functioning. Individuals who are eligible for DMH services may or may not be eligible for special education services. Other service agencies utilize their own internal eligibility standards and assessment procedures. Individuals who are determined to be eligible for other such services may or may not meet criteria for a medical diagnosis of an ASD and may or may not be eligible for special education services.

COMPARISON OF ASSESSMENTS: CLINICAL/MEDICAL, EDUCATIONAL, AND

OTHER SERVICE SYSTEMS

TABLE 1.2

	CLINICAL/MEDICAL	EDUCATIONAL	OTHER SERVICES
CRITERIA USED	Medical Diagnostic Criteria based on <i>DSM-IV-TR</i>	Eligibility criteria established by federal law under the Individuals with Disabilities Education Act (IDEA) and state regulations as articulated in the <i>Missouri State Plan for Special Education</i>	Agency-based criteria
EVALUATION PROCESS	Diagnostic evaluation is completed to determine if individual meets criteria for a medical diagnosis of ASD or another disorder. Re-evaluation is completed as indicated on a case-by-case basis.	Under Part C of IDEA in Missouri, children in the 0–3 year age range qualify automatically for First Steps early intervention services if they have a medical diagnosis of ASD. Under Part B of IDEA for students ages 3–21 years, evaluation for eligibility determination is completed to determine if student meets criteria under one or more of 13 education disability categories, including Autism. A need for reevaluation must be considered triennially but not more frequently than once a year unless the parent and school district agree otherwise.	Eligibility evaluation to determine if individual meets agency's eligibility criteria
ASSESSMENT PROCESS	May occur as part of or after diagnostic evaluation to identify individual strengths and concerns Results inform intervention across medical, educational, community, and home settings to minimize problems and maximize independent functioning.	Assessment instruments are initially used as part of the evaluation for eligibility determination to identify areas in which a potential disability adversely affects the child's educational performance.	Results inform the individual's needs within the context of family priorities and resources.
INTERVENTION PLANNING	May include recommendations for medical treatment, medication management, outpatient speech-language, occupational and/or physical therapies, behavioral therapy, psychotherapy, family counseling and supports, educational strategies, and accessing community services	Conducted by IEP team, of which parents are members The IEP addresses unique needs of the child and contains such items as annual goals, school-based services, environmental and instructional accommodations, and assistive technology. The IEP is reviewed and revised at least annually. A 504 plan may provide an alternative mechanism for classroom accommodations if a child does not meet eligibility for IEP services.	Recommendations focus on specific agency services and other related resources that may be accessed.
PLAN	Treatment Plan(s)	For 0–3 years, Individual/Family Service Plan For 3–21 years, Individual Educational Program	Service Plan

Integration of Plans and Programs

As Table 1.2 suggests, medical treatment plans, individualized educational programs, and service plans each contribute valuable information about the strengths and concerns of the individual with an ASD. These *Guidelines* recommend that professionals report findings from the assessments in a manner that facilitates usability across settings and allows families to synthesize this information into a comprehensive profile of the individual. If necessary, families have a variety of resources in Missouri that can assist with this process. Some of these resources are listed in Appendices E, H, and I.

Continuous Monitoring and Evaluation

Assessment is a continuous process. Professionals and families continually work together to monitor changes in the presentation and symptoms of the individual diagnosed with an ASD. As changes are observed, new assessments may be initiated by either the family, lead clinician, or primary care provider. Points of transition require close monitoring (e.g., transition from Early Intervention services under IDEA Part C to special education services under IDEA Part B; from school to work or higher education) and often require reassessment to facilitate transition planning. Service coordinators in local Regional Offices within the Division of Developmental Disabilities, Department of Mental Health, can assist families in this way, or the lead clinician may help the family develop an integrated plan.

Facilitation of Ongoing Care

Ongoing care for the individual and his or her family beyond ASD-specific services is critically important. Therefore, integral to the diagnostic and assessment processes is planning for follow-up services. This can take many forms. In some cases, the family is referred back to the PCP (if the PCP was not acting as the lead diagnostic clinician). The PCP, who is the lead healthcare provider close to the home of the individual with an ASD and her or his family, partners with the family to access services that meet the specific needs of the individual. The PCP is encouraged to continue ongoing consultation and collaboration with the lead diagnostic clinician and other specialty clinicians to address ASD-specific medical needs. At other times, follow-up is provided by the lead clinician. Regardless, careful and deliberate consultation with the family regarding their preferences for follow-up care is important.

Implications for the Future of ASD Services in Missouri

Members of the Missouri Autism Guidelines Initiative and sponsors of this project believe that ASD screening, diagnostic, and assessment services can improve. This publication has been developed to enhance communication among professionals who work with individuals with ASDs and their families and to serve as a foundation for training parents, healthcare professionals, educators, and others in related best practices. Another publication, *Navigating Autism Services: A Community Guide for Missouri*, helps families understand the services available for people with ASDs, how to access these services, and where to start. Together these two publications provide a roadmap for families and professionals to access and improve ASD-related services. (See Appendix E for additional information on the *Navigation Guide*.)

Summary of Best Practice Recommendations

Best practice recommendations appear throughout the *Guidelines* and are compiled here for quick reference. The page numbers indicate the location of each recommendation in the full *Guidelines* publication.

SCREENING

- All professionals involved in the care of young children are aware of developmental indicators of ASDs. PAGE 21
- All professionals responsible for the care of children perform routine developmental monitoring to identify children with atypical development. PAGE 23
- Higher risk children receive more intensive monitoring and screening. PAGE 25
- At a minimum, specific screening for ASDs occurs for all children at 18 and 24 months of age. PAGE 25
- A positive screening results in an immediate referral for further evaluation of developmental concerns. PAGE 28
- When indicators of ASDs are observed in the school setting, educational personnel discuss with parents the potential benefits of a diagnostic medical evaluation. PAGE 34
- School and community professionals are adequately prepared to assure timely screening, referral, and diagnosis of persons with ASDs. PAGE 34
- Community professionals elicit and respond to parents' concerns about their child's development and behaviors at every healthcare provider contact, including well- and ill-child visits. PAGE 35
- Parents are included as full partners throughout the screening and referral process. PAGE 35
- If developmental screening suggests an ASD, there is an immediate referral for further evaluation regardless of the age of the individual. PAGE 37

- At-risk children and their parents are referred to intervention services and community supports based on their individual needs, even prior to completion of the ASD diagnostic evaluation. PAGE 40
- Children at risk for ASDs and other developmental concerns are followed over time by primary care providers and other professionals in their community to ensure access to quality care. PAGE 40
- Information about a child's development is communicated to parents with sensitivity and understanding, noting both strengths and concerns. PAGE 41
- Effective communication with parents about their child's developmental progress is essential for early identification and intervention. PAGE 41

DIAGNOSTIC EVALUATION

- The diagnosis of an ASD is made as soon as possible to facilitate intervention and initiate family support. PAGE 46
- The lead diagnostic clinician is knowledgeable about typical child development; variability in presentation of ASD symptoms across age range, intellectual, and developmental levels; and non-autism spectrum disorders that can have symptoms similar to ASDs. PAGE 46
- The lead diagnostic clinician is familiar with the psychometric properties and utility of ASD diagnostic instruments. PAGE 47
- The lead diagnostic clinician is aware of the limits of his or her own clinical competence and utilizes standardized instruments, consultations, or referrals as necessary for accurate diagnostic decision making. PAGE 47
- The lead diagnostic clinician has the knowledge, experience, and clinical judgment to conduct comprehensive evaluations that include two core elements: the individual's history, and direct interaction and observation of the individual. PAGE 56
- The lead diagnostic clinician allots adequate time and materials to complete a review of relevant records, a thorough parent interview, and direct interaction and behavioral observation of the individual. PAGE 56

DIAGNOSTIC EVALUATION CONTINUED

- Face-to-face behavioral observation and interaction are essential components of diagnostic evaluation. PAGE 56
- Completion of standardized behavior ratings or other data collection procedures by professionals in multiple settings provides valuable information about the individual's functioning. PAGE 58
- The lead diagnostic clinician builds a partnership with parents and caregivers throughout the diagnostic evaluation process. This partnership begins by respecting parents' expertise about their child and focusing on parents' questions and concerns. PAGE 59
- The lead clinician is able to differentiate ASDs from other developmental or psychiatric disorders with overlapping symptoms. PAGE 71
- A family-centered evaluation entails spending sufficient time with parents to provide detailed feedback and answer all questions. PAGE 75
- Evaluation reports are written in a manner that is accessible and understandable to parents and other service providers who may be involved in providing therapeutic, educational, social, or rehabilitative services. PAGE 76
- Parents are encouraged to share the written evaluation report with other professionals who are providing ASD-related services, as appropriate. PAGE 76

ASSESSMENT FOR INTERVENTION PLANNING

- Assessment for intervention planning requires collaboration with family members to prioritize domains of functioning to be addressed based on family concerns, functioning, and access to resources, as well as clinical indicators, intervention history, and prior assessments results. PAGE 81
- Professionals involved in assessment for intervention planning understand the basic similarities and distinctions among the various service systems, including medical, educational, and other providers with whom individuals with ASDs and their families may be involved. PAGE 82
- Assessment requires careful examination of individual functioning across multiple domains to direct intervention planning based on the individual's unique profile of strengths and concerns. PAGE 83

- After initial assessment for intervention planning has been completed, the lead clinician remains available to the family to support coordination of care. PAGE 84
- Community collaboration is enhanced when results of clinical, educational, and other community-based assessments are available for consideration across settings and service providers. PAGE 84
- Professionals involved in assessment for intervention planning understand the role of assessment in development of an initial intervention plan and the need for continuous and ongoing assessment. PAGE 85
- Assessment for intervention planning requires involvement of professionals representing multiple disciplines. PAGE 86
- Professionals involved in clinical assessment for intervention planning have expertise in their fields and specific training and experience with ASDs. Professionals openly discuss their credentials and experience with ASDs with individuals involved in the assessment process including parents or other family members. PAGE 86
- Individuals with ASDs, their families, and/or advocates are encouraged to inquire about the training and experience of professionals when selecting service providers. PAGE 86
- Professionals involved in assessment for intervention planning consider available data from all prior assessments, including assessments conducted in clinical, educational, or other service settings. PAGE 87
- Although each essential component is explored for all individuals diagnosed with ASDs, assessment for intervention planning is tailored to the unique needs of each individual and his or her family. PAGE 87
- Assessment of cognitive and academic functioning is completed for all individuals diagnosed with ASDs. PAGE 88
- Assessment of adaptive functioning is completed for all individuals diagnosed with ASDs. PAGE 89
- For older children, adolescents, and young adults, assessment of adaptive functioning includes attention to skills and competencies required for transitions, such as transition from elementary to middle school or from home to residential living. PAGE 89

ASSESSMENT FOR INTERVENTION PLANNING CONTINUED

- Assessment of social, emotional, and behavioral functioning includes consideration of possible coexisting social-emotional difficulties that might impact intervention planning. PAGE 90
- Comprehensive assessment of social, emotional, and behavioral functioning is completed for all individuals diagnosed with ASDs. PAGE 90
- Comprehensive assessment of communication skills is completed for all individuals diagnosed with ASDs. PAGE 90
- All individuals diagnosed with ASDs require a comprehensive medical examination to assist in determining the presence of any associated medical conditions or health risk factors and to consider the underlying etiology of their neurobiological disorders. PAGE 91
- Assessment of sensory and motor functioning is completed for all individuals diagnosed with ASDs to facilitate intervention planning. PAGE 92
- Assessment of the family environment provides a context in which all essential components of assessment for intervention planning are considered. PAGE 92
- The lead clinician and any other professionals completing assessments clarify their current and future roles in the individual's care. PAGE 93
- Professionals talk explicitly with families about their concerns and the potential benefits of sharing relevant information with all service providers involved with the individuals with ASDs. The need for parental or individual consent to share information is discussed, and the important role that families can play in facilitating communication among providers is emphasized. PAGE 93
- Assessment reports are written in a manner that is accessible and understandable to parents and other service providers and contain practical recommendations for next steps. PAGE 94
- Following thorough discussion with family members, information about the standardized instruments used and specific test scores obtained are provided as part of the written report, when possible. PAGE 94

Other Resources Available for Families

A collection of resources is included in the Appendices of the full *Guidelines* publication and is available online at www.autismguidelines.dmh.mo.gov. Of particular interest to families:

APPENDIX C

CDC's *Learn the Signs. Act Early.* List of Developmental Indicators

APPENDIX H

Missouri: Focus on Autism, an outline of the state's initiatives in the area of ASDs.

APPENDIX I

Regional Office Points of Entry for the Department of Mental Health

APPENDIX J

Coordinated Early Intervening Services (CEIS), an overview of how Missouri's public education system approaches screening and services for students with ASDs.

APPENDIX E

Resources for Screening and Referral, parts of which are included here and on the following page.

Typical Social Development and Screening for Red Flags

- Centers for Disease Control and Prevention (CDC), *Learn the Signs. Act Early.* program
<http://www.cdc.gov/ncbddd/autism/actearly>
- First Signs' ASD Video Glossary, on-line tool to help parents and professionals learn about red flags for ASD
<http://www.firstsigns.org>
- Mid-Missouri Autism Rapid Response Initiative brochure, *Could My Child Have Autism?*
<http://www.dmh.mo.gov/developmentaldisabilities/officeofautismservices.aspx>. Click on Publications link
- Mid-Missouri Autism Rapid Response Initiative training modules, Understanding Autism (Free through University of Missouri Extension Program) <https://extweb.missouri.edu/courses/>

APPENDIX E (CONTINUED)

Accessing Diagnostic Services

Parents and caregivers can reference any of these directories to locate diagnostic centers, physicians, and other types of services:

- Hosted by Autism Speaks
www.autismspeaks.org
- Hosted by Autism Alliance of Greater Kansas City
www.autismalliancekc.org
- Hosted by Missouri Families for Effective Autism Treatment (MO-FEAT Autism Resource Directory)
www.mo-feat.org

Accessing State and Local Autism Services

A guide tailored to Missouri's system of care, *Navigating Autism Services: A Community Guide for Missouri*, includes basic services and where to go for assistance:

- State departments for early intervention and health care services, pages 7-8
- State departments providing support services for children and youth ages 3-21 years, pages 8-12
- Local, county-based funding or services provided by Senate Bill 40 Boards, page 10

<http://www.dmh.mo.gov/developmentaldisabilities/officeofautismservices.aspx>

Parent Education and Supports

- Autism Speaks, *First 100 Days*, created to assist families in getting critical information in the first 100 days after a diagnosis
http://www.autismspeaks.org/community/family_services/100_day_kit.php
- Support groups for parents, caregivers, and siblings including social skills groups
<http://www.dmh.mo.gov>. Type Autism Support Groups in the search field.
- Missouri Developmental Disability Resource Center
www.moddrc.org
- MPACT Missouri's Parent Training and Information Center
www.ptimpact.org
- Sharing Our Strengths—Missouri's Parent-to-Parent Support Network
www.sharingourstrengths.com
- Autism Society of America's on-line referral database
<http://www.autismsource.org>

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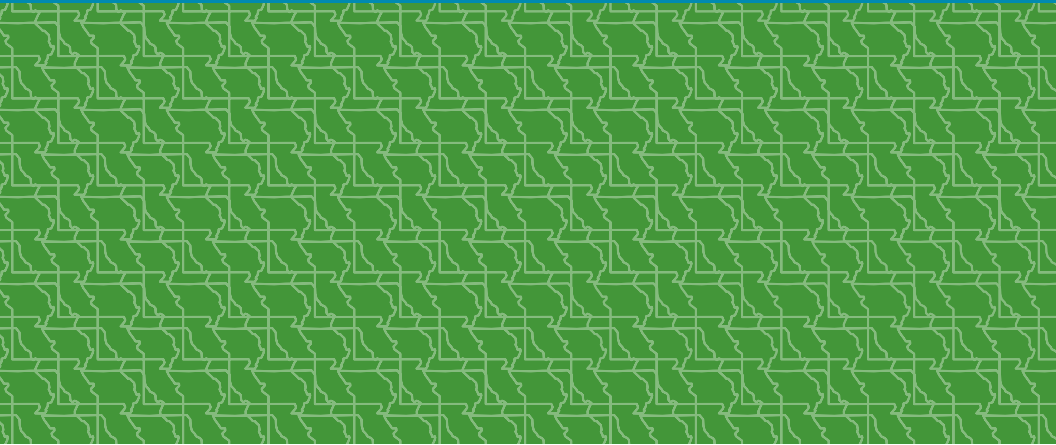
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